

Senate Bill 159

By: Senators Grant of the 25th, Unterman of the 45th and Thomas of the 54th

AS PASSED

AN ACT

To amend Article 1 of Chapter 1 of Title 31 of the Official Code of Georgia Annotated, relating to general provisions relative to health, so as to create the Hemophilia Advisory Board; to provide for a short title; to provide for legislative findings; to provide for duties, reporting, membership, and the selection of officers; to provide for related matters; to repeal conflicting laws; and for other purposes.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

SECTION 1.

This Act shall be known as and may be cited as the "Hemophilia Advisory Board Act."

SECTION 2.

The General Assembly finds that hemophilia and other bleeding disorders are devastating health conditions that can cause serious financial, social, and emotional hardships for patients and their families. Hemophilia and other bleeding disorders are incurable, so appropriate lifetime care and treatment are necessities for maintaining optimum health. Advancements in drug therapies are allowing individuals greater latitude in managing their conditions, fostering independence, and minimizing chronic complications. As a result, individuals are living longer and are healthier and more productive. However, the rarity of these disorders coupled with the delicate processes of producing clotting factor concentrates makes treating these disorders extremely costly. It is the intent of the General Assembly to establish an advisory board to provide expert advice to the state on health and insurance policies, plans, and programs that impact individuals with hemophilia and other bleeding disorders.

SECTION 3.

Article 1 of Chapter 1 of Title 31 of the Official Code of Georgia Annotated, relating to general provision relative to health, is amended by adding a new Code section to read as follows:

"31-1-10.

(a) The director of the Division of Public Health of the Department of Human Resources in conjunction with the Commissioner of Insurance shall establish an independent advisory board known as the Hemophilia Advisory Board.

(b)(1) The following persons shall serve as nonvoting members of the Hemophilia Advisory Board:

(A) The director of the Division of Public Health or a designee; and

(B) The Commissioner of Insurance or a designee.

(2) The following voting members shall be appointed by the director of the Division of Public Health, in consultation with the Commissioner of Insurance, and shall serve a three-year term:

(A) One member who is a board certified physician licensed, practicing, and currently treating individuals with hemophilia and other bleeding disorders and who specializes in the treatment of these individuals;

(B) One member who is a nurse licensed, practicing, and currently treating individuals with hemophilia and other bleeding disorders;

(C) One member who is a social worker licensed, practicing, and currently treating individuals with hemophilia and other bleeding disorders;

(D) One member who is a representative of a federally funded hemophilia treatment center in this state;

(E) One member who is a representative of an organization established under the Georgia Insurance Code for the purpose of providing health insurance;

(F) One member who is a representative of a nonprofit organization that has, as its primary purpose, the provision of services to the population of this state with hemophilia and other bleeding disorders;

(G) One member who is a person who has hemophilia;

(H) One member who is a caregiver of a person who has hemophilia; and

(I) One member who is a person who has a bleeding disorder other than hemophilia or who is a caregiver of a person who has a bleeding disorder other than hemophilia.

(3) The Hemophilia Advisory Board may also have up to five additional nonvoting members as determined appropriate by the director and the Commissioner of Insurance. These nonvoting members may be persons with, or caregivers of a person with, hemophilia or other bleeding disorder or persons experienced in the diagnosis, treatment, care, and support of individuals with hemophilia or other bleeding disorders.

- (c)(1) Board members shall elect from among the voting board members a presiding officer. The presiding officer retains all voting rights.
- (2) A majority of the members shall constitute a quorum at any meeting held by the Hemophilia Advisory Board.
- (3) If there is a vacancy on the Hemophilia Advisory Board, such position shall be filled in the same manner as the original appointment.
- (4) Members of the Hemophilia Advisory Board shall receive no compensation for service on the Hemophilia Advisory Board.
- (d) The Hemophilia Advisory Board shall meet at least quarterly and at the call of the director or the Commissioner of Insurance or the presiding officer and follow all policies and procedures of Code Sections 50-14-1 through 50-14-6, relating to open and public meetings.
- (e) The department shall provide reasonably necessary administrative support for Hemophilia Advisory Board activities.
- (f) The Hemophilia Advisory Board shall review and make recommendations to the director and the Commissioner of Insurance with regard to issues that affect the health and wellness of persons living with hemophilia and other bleeding disorders, including, but not limited to, the following:
 - (1) Proposed legislative or administrative changes to policies and programs that are integral to the health and wellness of individuals with hemophilia and other bleeding disorders, including access to appropriate health insurance or similar health coverage;
 - (2) Standards of care and treatment for persons living with hemophilia and other bleeding disorders, taking into consideration the federal and state standards of care guidelines developed by state and national organizations, including, but not limited to, the Medical and Scientific Advisory Council of the National Hemophilia Foundation;
 - (3) The development of community based initiatives to increase awareness of care and treatment for persons living with hemophilia and other bleeding disorders; and
 - (4) The coordination of public and private support networking systems.
- (g) The Hemophilia Advisory Board shall, no later than six months after the effective date of this Code section, and annually thereafter, submit to the Governor and the General Assembly a report of its findings and recommendations. Annually thereafter, the director of the Division of Public Health, in consultation with the Commissioner of Insurance, shall report to the Governor and the General Assembly on the status of implementing the recommendations as proposed by the Hemophilia Advisory Board. The reports shall be made public and shall be subject to public review and comment."

SECTION 4.

All laws and parts of laws in conflict with this Act are repealed.